customers come to they shop and see that I have leishmaniasis on my nose, they think that we haven't cleaned our shop and our house. That is why I got leishmaniasis.

Social Life.

Hospitality is an important determinant of social standing in Afghan society, so visiting and receiving friends and relatives was a topic of concern for both gender-categories. Whereas most CL sufferers reported a degree of support from their close family, more remote relatives and friends were felt to be more harsh, perhaps reflecting a different balance of gains and losses in the interaction. Some respondents reported that nobody in their family was willing to accompany them on social visits, and this was particularly true for young women who by Taliban rules must be accompanied by a male relative. A feeling that shame was being shared by the whole family was commonly expressed.

Fs Whenever guests come to our house, my family tells me not to greet them. They say "They shouldn't see you. You should stay in a separate room and lock the door, so the guests won't see you. If the guests see you they won't eat in our house and will say that they will get leishmaniasis as well".

Fs Once guests came from Pakistan. During dinner I covered my nose because I didn't want them to see my leishmaniasis. When they asked why I covered my face, I told them that I was sick. In the morning, when they were eating breakfast, they saw my leishmaniasis on my nose. As soon as they found out they left the house.

Concealment of lesions for men was generally only possible if the lesion was on the arm or leg; for lesions elsewhere, attempts at concealment could attract more attention than the lesion itself and this was true also for women in the home, as for the woman above. The strong reaction of others in social situations can create a dilemma for those who are able to conceal their lesions; having CL oneself does not necessarily prevent the rejection of others.

Mm I went to a funeral ceremony during lunch. A man, with leishmaniasis all over his hands, came and sat next to me. I thought, what to do if the lunch is soup (*where people dip bread with their right hand into a common bowl*), because he had leishmaniasis all over his hands . I felt very bad, and I thought it would be better not to eat with him, but fortunately there was rice. He found out that I didn't like him and he wanted to go and sit somewhere else, but everybody tried not to eat with him. At last he left the room and I thought that, although I have leishmaniasis on the feet myself, it is very sufferable. It makes people leave, to stay at home and to lock themselves in a room in order to heal and to return to normal life again.

One of the major concerns for young people, especially women, was their appearance and ability of aspire to an ideal of beauty; CL was felt to seriously undermine their prospects for marriage. Both active lesions and scars were a concern, particularly on the face.

Fs Everyone in my family calls me soldana, even my fiancee. My mother- and brothers-in-law asked him "why are you going to marry a soldana-ei girl?".... Once my fiancee asked me to go with him to his native province. I refused because I had other things to do. He then said: "if you don't want to come with me I will marry with someone else". I felt very disappointed because he is the only one, he should be my supporter, but instead he said humiliating things like "you are soldana-ei" or "I don't like you, you have leishmaniasis". Sometimes at night I can't sleep because I keep thinking about what to do in future. Scars will be left and will create many problems for me.

Ms One of our relatives has lost half of his nose because of leishmaniasis. He has had leishmaniasis for a long time, and whenever he wants to go to parties, other relatives tell him not to come. They told him things like: "everybody will stare at you in a mocking way", "you will be pointed at", and "you will look ugly". Now I have leishmaniasis and when I see him, I remember all these things, and I don't want to go to parties.

Religious life

Several men reported that leishmaniasis caused problems in taking their ablution and staying ritually clean throughout the prayer. They felt that others saw them as unclean and they were deterred from praying at the mosque. None of the women respondents mentioned this as a problem, presumably because women traditionally do not go to the mosque.

> Mm. Once I was praying in the mosque and pus started to run out of the leishmaniasis on my face. I went out and cleaned it, but when I came back it started running again. I left two more times to clean it, but the pus just got worse. And then people started sniggering at me. There were some Taliban there looking furious with me. I couldn't put up with that circumstance and went away. I used to go to the mosque very often, but now I have decided not to go there anymore.

DISCUSSION

The principal finding of the study is that CL in Kabul was found to be associated with significant social exclusion and stigma. The study population was representative of cases being treated in a CL clinic, about 75% of whom reported feeling significantly stigmatised by their disease. . Stigma was generally enacted, ranging from well-meant and minor domestic restrictions (e.g. not sharing towels) to quite punitive measures where respondents felt physically and emotionally isolated. Severity and visibility of the lesions were strong modifying factors, but age, sex and a past experience of CL within the family were also found to play an important part.

Those who experienced more problems seemed to have more to say in the FGDs. It would have been preferable to have been able to conduct interviews of families within their own homes where cross-checking of the data with family members would have been possible, but the political and social constraints operating in Kabul made this impossible. The FGDs of spouses, although of limited size, seemed to generally confirm the reports of the sufferers. Additionally, whilst the investigators have made a conscious effort to be fair in their conclusions and selection of quotes, it is hard not to be influenced by the more striking reports. A future study could provide greater validity by including family interviews and a more quantitiative approach to data collection.

Women felt the consequences most acutely in the home where their core traditional role as carers of the family was seriously undermined. Many women reported feelings of disappointment and resentment at not being allowed to handle children, prepare meals or eat with their families. As in other studies of disease stigma, young women felt disfigured and unattractive, and this threatened their self-confidence and ability to attract a husband. One young woman spoke of suicidal feelings; whilst this may seem to be an over-reaction to CL, within the context of the already difficult situation in Kabul it may be understandable.

Restrictions on women, particularly younger women, were often reported to be imposed by a male relative, whereas men decided on their own restrictions. However this was not universal, particularly where a man was seen as an infectious threat to children. Married women often expressed fear of being blamed for spreading the disease to others in the family. The tendency of sufferers to report slightly harsher treatment than was confirmed by their unaffected spouses could have several interpretations. Spouses may have been embarrassed to confirm their uncaring attitudes, or sufferers may have exaggerated the story to gain sympathy in the group. There was evidence that sufferers themselves felt dirty and contagious ('felt stigma'); this may have lead them to overestimate any stigmatising reactions they experienced or to impose harsher restrictions on themselves than were required by others.

Men tended to report problems with work, mixing in public, meeting friends and socialising. Unemployment is very high in Kabul and several men mentioned losing precious jobs or being unable to find even casual work. If men can't work their role in the family is seriously undermined and the family

may have to rely on relatives or resort to begging. Young men often reported a fear of socialising and being jeered at on the street by their peers.

Whilst it was clear that families in Kabul are close and generally supportive, those outside the immediate family were reported to be less supportive. In particular, several respondents described feeling disempowered and marginalised in a public or work setting, where others could easily use their CL against them. Socialising with friends and relatives was reported to be a problem for most sufferers of both sexes. Afghans are very proud of their hospitality, and the Islamic faith attaches great importance to cleanliness. If hospitality cannot be offered or received because a family member is seen as unclean or an infectious threat to others, then shame was reported to be deeply felt by the whole family.

Conditions of life in Kabul at present are exceptionally harsh; the widespread poverty and destruction and the continuing war have been compounded by the imposition of a strict Islamic code which is not traditional to Kabul (Marsden, 1998). The harshness of conditions in Kabul may have reduced the capacity of families and communities or cope with the additional burden of CL and coping strategies described by CL sufferers in Kabul seemed to be very limited, with little evidence of tolerance or understanding by others. Where kindness was shown it tended to be amongst families with a past experience of the disease. Concealment of CL was difficult, and was generally only used by women in public. Social isolation was a much commoner strategy, but seemed to carry a high economic, social and emotional price.

In most affected areas of the world CL is chronically endemic, often for centuries (Desjeux, 1991). Over time tolerance and understanding of the disease may evolve, and more effective coping strategies may be developed. However, the disease is relatively new to Kabul. The relative lack of knowledge in Kabul about how CL is transmitted and that infection generally leaves life-long immunity are indicators that people generally are still acquiring knowledge and experience which might assist them in coping with the disease. So whilst for the reasons above, the conclusions of this study cannot be automatically extrapolated to other areas where CL is common, there is sufficient evidence to suggest that the issue of social stigma should be considered elsewhere and if indicated, measures should be implemented to reduce it.

The source of stigmatising attitudes towards CL can be considered in 2 categories. One is largely knowledge-based whereby there seemed to be widespread and inappropriate fear of direct or indirect transmission of CL to others. The second is based more on personal prejudice; this included feelings of disgust, and an association with poor hygiene, war and sinfulness, all of which tend to create more of a 'guts feeling'. Clearly these are not separate categories in the real world, and most of the respondents in this study seemed to express degrees of both, and it seems likely that they reinforce each other.

Whilst personal prejudice may be very hard to change, the unreasonable fear of transmission might be correctable through appropriate health education. The central message of such a programme would be that CL is not normally transmissible by touch, as witnessed by the very few CL clinic workers who have ever contracted the disease. Such a message could be delivered through mosques, schools, clinics and local radio, and could be locally sustainable with minimal resources. This might be particularly appropriate for Kabul where resources for proper treatment are hopelessly overwhelmed. It is important that the impact of such health education should be properly evaluated. If successful, it could do much to reduce the unnecessary suffering due to this unpleasant disease.

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Footnote: [1] Codes indicate the respondents; Fm (married woman), Fs (single woman), Mm (married man), and Ms (single man)

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SOCIAL AND PSYCHOLOGICAL CONSEQUENCES OF CUTANEOUS LEISHMANIASIS IN KABUL, AFGHANISTAN.

HEALTHNET INTERNATIONAL

IN PARTNERSHIP WITH NORWEGIAN CHURCH AID.







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FOREWORD

Although the focus of this work was the stigma associate with cutaneous leishmaniasis (CL) in Kabul, the unique social setting of Kabul requires some description as it is relevant to all aspects of social life in the city.

During the 1960s and 1970s the urban areas of Afghanistan embraced modernisation; in Kabul there was a well developed infrastructure with excellent levels of education. The Islamic 'burqa' which covered the entire body had been made optional in 1959, and modern fashion and discoteques were common.

Since the Soviet invasion in 1979 there has been war in Afghanistan. This was initially concentrated in the rural areas where traditional Afghan fighters (Mujahadeen) resisted Soviet occupation. Following the Soviet withdrawal in 1989, the scene of the war shifted to an intense and bloody struggle between various Mujahadeen factions. Kabul experienced the worst of this in the 1992-5 period when the city was divided between competing factions who proceeded to rocket, bomb and loot large sections of the city until only mine-infested rubble and wreckage remained. At present Kabul is probably the most war-damaged city in the world; about 40% of the city is completely destroyed and its population has fallen from over 2 million in the 1980's to about 1.2 million in 1998.

Against this background of devastation, the Taliban movement, rooted in the traditional and conservative south of Afghanistan, emerged in 1992 and has progressively taken control of the country. In September 1996 the Taliban took Kabul and proceeded to impose strict Islamic law which was not at all traditional to the population.

Currently life in Kabul is very harsh. There is widespread poverty and destruction, with almost no functioning infrastructure. Most of those with money or skills have long fled the country and the economy is very depressed. Women in particular have been subject to severe restrictions; they are not allowed to work except in the health sector and must wear the 'burqa' and be accompanied by a male relative in public. Girls are forbidden to receive education, and the few boy's schools that are open are hopelessly ill-equipped. Men must grow untrimmed beards, wear traditional dress and attend the mosque regularly. Music or images of living things are forbidden. Minor offences are often dealt with by summary beatings and severe offences with public amputations or execution.

Destruction, population movement and poverty have been associated with the rise of a number of infectious diseases, and CL is one such example. Whist the current epidemic of CL has its origins in the physical environment, its impact must be seen in the context of the unique social environment that currently exists in Kabul.

In 1997, Norwegian Church Aid funded the HealthNet leishmaniasis control programme, with a focus on disease prevention, treatment and local capacity building. During the course of the work it became apparent that the social impact of CL needed to be addressed, and this study was undertaken as an initial evaluation of the problem. As a result of this study, HealthNet is seeking in 1999 to implement a programme of health education to reduce the social and psychological impact of CL.

ABSTRACT

During the last 5 years, cutaneous leishmaniaisis (CL) has become epidemic in Kabul, Afghanistan where about 5% of the population was affected in 1997. Patients attending a leishmaniasis clinic in Kabul frequently reported feeling stigmatised by their disease or excluded from normal activities. In order to investigate this process, a series of focus group discussions and individual interviews were held with adult sufferers of CL and their spouses. CL was reported to provoke feelings of disgust and fear of contagion, and was felt to be associated with low personal hygiene and sinfulness. Most informants reported significant feelings of rejection and sometimes this could be very disabling. Overall it seemed that women suffered the consequences of infection with CL more than men, although both sexes experienced problems. Women felt unattractive, and that their marriage prospects were reduced or their position in the home was undermined. Men experienced problems with being seen in public, fulfilling a work role and praying at the mosque. Both men and women found that visitors were reluctant to come to their houses and that it was difficult to visit friends or attend social functions. Knowledge about how CL is spread was generally low, and this may reflect the fact that CL is a relatively new disease to Kabul. Stigmatising attitudes seemed to be much less common amongst families with a past experience of the disease. It seems likely that a relatively simple programme of health education might significantly reduce the social rejection applied to CL sufferers.

KEY WORDS

cutaneous leishmaniasis, stigma, gender, Afghanistan, focus group discussion.

INTRODUCTION

Social and psychological consequences may form a major component of the suffering and disability associated with disease. This is particularly true of dermatological conditions occurring on exposed skin. Such lesions may look disgusting, are difficult to hide, and may create an unreasonable fear of transmission to others. In addition, they may be interpreted as markers of personal characteristics (sinfulness, dirtiness, poverty). The resulting social exclusion, whether enforced or self-imposed, often causes unnecessary suffering and economic loss.

During the course of treating more than 5,000 cases of cutaneous leishmaniasis (CL) in Kabul, patients frequently reported that they felt marked by their disease and that special rules of exclusion were applied to them. This accords with Gillmore and Somerville's (1994) definition of a stigmatising process; 'the identification of a bad or negative characteristic, in a person or group of persons and treating them as not deserving of respect or less worthy than others on this basis'. Goffman (1963) has described two types of stigma: enacted stigma refers to sanctions individually or collectively applied to the victim, and felt stigma to feelings of shame, an oppressive fear of enacted stigma and concealment of the condition. The stigmatising process may be modified by the perceived gains and losses of interacting with a marked person (Jones 1984).

There are few published studies on the stigmatising effect of CL or other skin conditions in developing countries. Weigel et al (1994) in Ecuador found that women felt that scars or active lesions of CL reduced their prospects for marriage and Vélez et al (1996) in Colombia reported that men avoided women with CL for fear of contracting the disease themselves. Vlassoff (1996) has described the impact of leprosy on family relations and marriage in India; while both men and women were negatively affected, women suffered more isolation and rejection because they were deprived of personal contact with others in the domestic environment where they were accustomed to receiving their greatest emotional rewards. Ovuga et al. (1995) found that the skin lesions of onchocerciasis were reported as stigmatising; those affected felt rejected by others and isolated from their communities, often choosing to spend most of their time in the safety of their homes.

Gender is an important modifying factor in looking at social consequences of disease, but it is important that the concept of gender should not be restricted to reproductive health of women but should include a wider view of social, economic and personal factors (Rathgeber and Vlassoff, 1993). This is particularly

relevant to Kabul where already strong traditional gender roles have been increased by the imposition of a strict Islamic code by the ruling Taliban authorities (Marsden, 1998); in this setting it is important to include the wider roles of both sexes, as each has highly specific but inter-dependent roles and responsibilities.

The purpose of this study was to make a preliminary description of the social and psychological consequences of active infection with CL in Kabul, and to indicate whether such consequences might be reduced by a relatively simple and locally sustainable programme of health education.

BACKGROUND

Cutaneous leishmaniasis in Kabul

CL in Kabul is caused by a flagellated parasite (Leishmania tropica) transmitted from person to person by the bite of a female sandfly (P. sergenti). The incubation period is long (3-12 months), so that an association with a sandfly bite is not at all obvious. Although it is theoretically possible to transmit the infection by direct inoculation from one person to another, this must be a very rare occurrence in practice (Ashford, 1987).

CL nearly always affects exposed skin; approximately half of the lesions occur on the face, with the remainder occurring on the upper or lower limbs. The number of lesions varies from 1 to more than 20, the size varying from about 1 cm to more than 10 cm in diameter. The disease starts as a small red spot, progressing to a nodule which usually tends to ulcerate, crust and weep a blood-stained fluid. The lesion tends to heal over the course of about 1 year, although some cases become chronic, taking up to 10 years to heal. On healing, a characteristic flat cribriform scar is left, sometimes with loss and deformity of underlying soft tissues. A single infection usually confers life-long immunity.

CL is common many in parts of the Middle East and South Central Asia, tending to occur in towns and villages where people live in close proximity to sandflies (Desjeux, 1991). Whilst CL has been endemic in other parts of Afghanistan for centuries, it has only been known in Kabul over the last 30 years. During this time the incidence has slowly increased, with a large (5-10 fold) increase in incidence following the war-related destruction and population movement which has affected Kabul since 1992. Currently about 5% of the population is affected. All ages and both sexes are more or less equally affected (Ashford et al, 1992, Hewitt et al, 1998). Rowland et al (1998) found that CL is well known and accurately recognised by Afghan communities by its local name of '*soldana*' (meaning 'the sore of a year').

MATERIALS AND METHODS

The particular conditions in Kabul during the study period imposed various constraints: access to female patients and staff was difficult, especially for the male expatriate project manager; there was a lack of staff trained in social survey techniques; the use of tape recorders was not officially permitted; and the work was part of an aid programme with many competing demands on time and resources. Towards the end of the study period there were political problems which eventually led to the suspension of the aid programme and the expulsion of expatriate staff from Kabul in July 1998. For these reasons, the methods used were confined to focus group discussions (FGDs) and individual interviews held in an upstairs room of a leishmaniasis clinic. The data were collected intermittently over a 5 month period from the end of February until the end of July 1998.

Selection criteria were adult clinic attenders with moderate or severe CL, usually affecting the face or hands. Since acceptance for treatment was already based on criteria of severity, almost all clinic attenders were suitable for inclusion in the study. However, about 35% of milder cases requesting treatment at the

clinic were turned away, and an estimated 20% of CL cases in the community did not bother to seek treatment. So the sample studied was representative of the more severe cases, constituting about 50% of all CL cases. Refusal to participate was rare.

Eight focus group discussions (4 male and 4 female) of CL sufferers were held, each of approximately six to ten participants. Four 'paired' FGDs were also held; each pair consisted of one group of sufferers and a simultaneous group of their unaffected spouses conducted in a nearby room. Two of the 'paired' groups consisted of male sufferers and unaffected wives, and 2 of female sufferers and their unaffected husbands. An additional 14 individual interviews were conducted: 3 with women (one married, two unmarried) and 11 with men (9 married, 2 unmarried). There were more male than female interviews due to the increasingly difficult access to female respondents in the later stages of the study. A total of 84 informants participated, with a mean age of 28. In accordance with local law, male and female participants were kept separate at all times.

FGDs were led by male and female teams. Each team consisted of two clinic staff-members who were briefly trained in the roles of group moderators or recorders. Their educational backgrounds were at the level of locally trained nurses or laboratory technicians. The FGDs and interviews were all discretely tape recorded (with consent of all participants). The recorder of the groups made a note of the atmosphere in the group and the way the group functioned. At the end of each session, the moderators and recorders were de-briefed with the principal investigator (HR). Tapes were translated into English by a translator and these tapes were transcribed by a typist.

The main question for the FGDs and interviews was 'what are the consequences of ACL on your daily lives?', with a secondary question of 'how do you thinkleishmaniasis is spread?' . Group moderators were instructed to allow the discussion to flow freely on these topics; participants were asked to emphasise personal experience and opinion and to encourage a discussion. Moderators were cautioned against allowing the group to only express negative feeling, and to encourage those who did not experience serious problems. The FGDs of affected and unaffected spouses focused on how the disease had affected their relationship. Individual interviews were conducted to explore in more detail the issues raised in theFGDs.

Groups were served tea and cakes, and the first 20 minutes were allowed for social chat. At the start of the group meeting, all participants including the moderator introduced themselves to their neighbor, who then introduced them to the group. Group discussions generally lasted for about 1½ hours.

Data were analysed by thematic analysis of the transcripts and discussions with the field staff by the 2 main investigators (HR and MK). General themes were identified and categorised into events affecting the daily life of respondents; these included home life, public life (work and bazaar), social life and religious life. Many statements were found to overlap categories.[1]

RESULTS

KNOWLEDGE AND BELIEFS ABOUT CL.

A wide variety of beliefs about the transmission of CL were expressed, mostly involving some sort of contact with an infected person, with insects of various sorts, with dirt, sewage or with dogs. War and God were commonly cited as underlying causes. A number of informants thought that CL could be spread through talking to an affected person. Both men and women often referred to the importance of personal hygiene in order to avoid leishmaniasis.

> Fm I have given birth and after a few months he [my son] got leishmaniasis on his face. I used to share the towel with him, and I think that I got leishmaniasis from him, because I washed his face and I touched his leishmaniasis and now I have leishmaniasis on my hand.

Many respondents recognised a connection with insects, either through their bite or touch, but none seemed to name a particular type of insect. In fact, small flying insects seem to share the same name (*pasha*) in Kabul. Sandflies, although very small, have very distinctive habits, and none of these were described by respondents. Being touched and bitten by insects were mentioned; mosquitoes sit in dirty water during the day and at night they come to the houses and bite human beings; mosquitoes transmit microbes from one

place to another ; mosquitoes takes pus from a person (or streetdog) with leishmaniasis. The appearance of many insects in Kabul was generally attributed to the dirty environment and dirty water.

M A bad smell is coming from the latrines during summer. That makes good circumstances for mosquitoes to grow. That is the reason for the many cases of leishmaniasis.

Street-dogs (currently very common in Kabul) were often thought of as sources of leishmaniasis, especially if they had visible sores. One woman mentioned that her daughter probably got leishmaniasis because she was bitten by a dog.

Fm My son and daughter brought a street dog from outside. They poured water over him, and I think that my son and daughter got leishmaniasis from that dog.

Two men described how ordinary wounds became leishmaniasis after they came in contact with dirt while cleaning a house. Dirty water was identified as a cause of leishmaniasis both by its association with insects and through dirty water itself.

During the worst fighting in Kabul (1992-1995) there was widespread environmental damage, mortality, poverty and population movement. Since this time, leishmaniasis has become very common in Kabul, and most respondents linked the spread of CL with the war. Dead bodies left in the street, gunpowder and migration to and from Pakistan were named as the source of CL by several informants.

Mm People say, and I believe, that leishmaniasis is sometimes transmitted through the corpses and dead human bodies which were left in the streets and wells during the war.

Fs Pakistan is very hot, particularly in the summer, and hot weather causes many diseases. The number of cases with this disease increased since the time people migrate to Peshawar (Pakistan) to Kabul. When people go to Peshawar they take leishmaniasis from there and when they come to Kabul they transmit it to the healthy ones.

Several times people mentioned that God creates everything, including leishmaniasis. For one of the informants this was seen positively as the reason that his family treats him well. Others saw it as a punishment from God:

Mm All diseases are from Allah. He doesn't create a disease without reason. I think it is because of the war and fighting. If you commit a sin or you have done something wrong, you will get the punishment later on. So I think this disease is from Allah. I don't know, I haven't committed a sin, but it is from Allah

Fs My sisters and brothers call me soldana-i and they say "you have done something wrong" or "you committed a sin". They don't believe that I'm innocent.

None of the informants spontaneously mentioned immunity. Of the 7 men who were specifically asked, four thought that they would be immune following infection with CL and 3 had been told so but were not sure.

A very commonly held belief, apparently shared by some health workers in Kabul, is that there is a male and female type of CL. The female type consists of large, wet and multiple lesions and is generally a much worse disease. The male type consists of dry solitary and smaller lesions. Both men and women are believed to be equally affected by the male and female form of CL. One respondent explained that the female disease must feed off the victim in order to lay her eggs, so the disease is worse.

Mm The female one will be on your hand. Then you will get more leishmaniasis. That is why I have 25 leishmaniasis. The male one is better: not better, but I mean, if you get a male leishmaniasis it will be just one leishmaniasis. The female one will spread and you will get more than ten or twelve leishmaniasis.

Two men mentioned that they heard from others that leishmaniasis can cause cancer and that this greatly added to their fear of the disease.

CONSEQUENCES OF CL ON DAILY LIFE.

Overall the majority of respondents reported some degree of feeling stigmatised or excluded by their disease. This seemed to be the result of both a fear of contagion and an association with dirt, low personal hygiene, sinfulness and disgust. Some informants expressed strong feelings of shame or anger. However, there was a significant minority, about 25%, who had little to say or who reported that their disease was generally accepted by others. It is clear that those who were experiencing problems had more to say, and this constitutes a potential source of bias in presenting the data.

Women seemed to be more able to express their feelings in the groups than men, and there was an overall impression that women suffered more. Unaffected spouses generally confirmed the reports of their affected partner, although they seemed to report that they were more tolerant than their affected partner perceived them to be. Wives generally seemed to be more tolerant and caring of their affected husband than husbands were of their affected wives.

Coping strategies were largely confined to concealment of lesions, which was slightly easier for women in public, and an acceptance of a degree of isolation. Although close family members were generally more supportive than strangers, these coping strategies were much harder to implement within the home.

Home and Family life

Special restrictions on CL sufferers were frequently reported to apply in the home. It seemed that the perceived need to isolate CL sufferers from others readily developed into a more personal rejection. Feelings that the disease had stimulated a more caring attitude in the home were very rarely expressed. Reported stigma was generally enacted; an insulting word, *soldana-ei* was commonly reported to be used against CL sufferers, leading to a general feeling of victimisation.

> Fs. I don't know how I got leishmaniasis. .... My nephew got leishmaniasis from me because he used the same towel I used. My family told me that I should separate my things from the rest of the family. I cried and told them that I don't want to eat separate from the others. But I was told by them that they are not interested to eat with me anymore. I never go anywhere.... Everybody in our family stares at me in a mocking way, particularly the mother-in-law of my sister. They call me soldana-i. And when I want to talk with them they say "go away soldana-ei, we don't want to talk to you, because, if we talk with you we will all get leishmaniasis"

In Kabul families are close; they eat together from the same plate, share glasses and towels and sleep together. One of the commonest restrictions reported by CL sufferers was the use of a separate towel which was seen as an important source of contagion since blood and pus from the wound sticks to it. Some respondents were required to eat separately from the family with his/her own plate, cup, utensils and not to share a bed with healthy family-members. Women with CL often reported that they were not allowed to cook for the family. This made them feel marginalised and isolated, but was significantly reduced if substitute labour was available within the household.

> Fs I have leishmaniasis on my nose. Nobody of my family wants me to drink from the glass they drink from. They try to stay away from me as well. It is a very bad and dirty sore. Everyone feels disgust towards me.

> Fm My little son told me "mother, you shouldn't cook the lunch. If you cook, your leishmaniasis will fall in the pot, and if we eat it we will get leishmaniasis as well".

There was a strong feeling that families acted as units; the well-being of the family rather than that of the individual had priority. This seemed to over-ride any need to show special kindness or attention to those affected with CL, as shown by a healthy young man when referring to his small brother withleishmaniasis.

> Ms I have a little brother with leishmaniasis. He has been told by us, and he decided himself, to separate his towel, plate and other things. We stay away from him. He feels very disappointed and sad, but what to do?.... I don't want my mother and others to become affected withleishmaniasis.

Many CL sufferers reported a loss of physical contact with their families resulting in a sense of emotional isolation. Couples do not touch or cuddle in public in Afghanistan and contact with children is an important source of physical warmth and reassurance which was denied to CL sufferers. Physical separation was often reported to be self-imposed, especially where children were perceived to be at risk.

> Mm A son of mine is born recently. My wife has leishmaniasis on her hands. She doesn't cuddle up our son, although I have told her that she'd better cuddle him up.

A past experience of CL seemed to soften attitudes to the disease, especially amongst men. A woman described how when she and her son both had CL her husband was very rejecting and upset, but then he too became infected and is now supportive and kind; the experience seemed to have drawn them together. Another man described his own experience with CL:

> Mm When I was 12 years old I had leishmaniasis on my feet. I can't explain how painful it was. I couldn't sleep well, it was pussy and water was coming out of it. I had to change my clothes everyday and the bed, where I slept in, became very dirty. It was very painful and I felt very upset and disappointed about leishmaniasis. And now when my wife has leishmaniasis, I try to convince my wife to be happy and to forget about her leishmaniasis. It is a very bad disease, and it makes that people sometimes behave rude.

Men reported fewer problems in the home resulting from CL. When restrictions were reported by them, they tended to be self-imposed. In general wives appeared much less rejecting than husbands, tending to report the need to support their husband 'no matter what'.

> Fm You know better that the husband is the only supporter of women, particularly in this desperate situation where there is no one to support women. We should respect and obey our husband and try to keep him happy. We shouldn't tell him "look at yourleishmaniasis". If we had leishmaniasis, our husband would tell us this, or would use some humiliating words. But we want to be kind. We want to be supportive by telling him that his leishmaniasis will get better.

Women tended to express feelings of rejection and isolation more frequently than men, and one girl said that she sometimes felt suicidal. Some women expressed anger at the situation, as with this 25 year old woman with multiple facial lesions:

> Fm. My husband started behaving violently since I have leishmaniasis, and then a month ago my son became infected and he went crazy since he told me not to touch our son. He often says I am useless and stupid and if my face does not heal soon he will take another wife. He says I bring shame to the whole family, but its not my fault. I feel so angry I want to tear the leishmaniasis off my face and push it into his throat.

Public life: work and the bazaar.

Both men and women with CL reported frequent problems in public, although these seemed to be greater for men presumably because they go out more and also find it harder to conceal their lesions. Generally, strangers were reported to be more rejecting than sufferers' own families. The following example describes how a woman was holding onto a rail on a bus, and one of the passengers warned the others not to touch the rail:

Fm When you go by bus, people don't do anything to help you to get into the bus. I have leishmaniasis on my hand and one time I was on a bus and used the rail to hold on. Another woman called out to the others on the bus 'We shouldn't touch this. If we touch it we will getleishmaniasis from her'. I felt very humiliated and didn't want to ride on the bus again.

Men in Kabul greet each other with an embrace, and frequently touch or hold hands in public. Many men reported that having CL made this difficult and embarrassing; whilst an embrace was rarely refused, it was clear to the sufferer that others would like to avoid it. As a result, some men described an unwillingness to go out or to meet people they knew. For younger men the problems seemed to be more directly expressed: several described been jeered at in the street, leading to a fear of going out or looking for work or education.

Mm Even the streetboys, when they see me they yell: 'the Red Cross car is coming!' They mean that I have leishmaniasis on my face which looks like the sign on a Red Cross car. That is very hard for me. Even if you say something to them, they will tell you something rude.

Paradoxically, the restrictions that have recently been imposed on women in Kabul were sometimes seen as an advantage. One girl was grateful for the closure of girls schools by the Taliban authorities, thus saving her from feeling tormented by her classmates over her leishmaniais. The imposition of the *burqa* (cover of the whole body) in Kabul could also be an advantage as it enabled concealment of facial lesions, although not all women could wear the *burqa* as the material rubs against the lesion. In such a cases they were in an even worse position since they were unable to leave the house at all (the *burqa* is compulsory in Kabul).

Fs I haven't been called names by people in the bazaar and they didn't use humiliating words, because my leishmaniasis is on my face and I cover my face with the burqa, so people can't see my face.

Several informants described how they had lost authority or felt disempowered from interacting in public or managing their affairs. In these cases it seemed that leishmaniasis was being used against them for an ulterior motive, and that the sufferer felt defenseless.

Fm Once I went to my nephews' school to make a complaint. I went to see his teacher to tell him to take care of his lessons. When my nephew came home later he told that the teacher told afterwards: "Nowadays everyone is speaking, even that soldana-ei aunt of you. Instead of coming to the school she should take care of her lesion. She should first treat her leishmaniasis and then come to talk with me and make those kind of suggestions".

Ms I used to work as a conductor in a bus between Kandahar and Kabul. Once, when I wanted to collect money, a young Kandahari man asked how much he had to pay. I told him 120,000 Afs. Then he said: "Oh, look at your nose, and then you ask me for money". I was very disappointed. The driver, who is my relative, said: "it is better to stay quiet because patience is bitter, but will be a sweet fruit." I was very disappointed and wanted the ground to split, so I could go inside. I didn't want to live anymore. I left the work and told myself that it is better to stay at home and not to work, not to hear the sarcastic words or to see the mocking stares of people.

Many men expressed frustration and anxiety about not being able to work with leishmaniasis, usually because the lesion was judged by others to be socially unacceptable in a work setting. None of the women described work problems, except to express frustration that current law prevents them from replacing their husband if he is unable to work through CL. High unemployment in Kabul means that employers can easily afford to reject CL sufferers, and in the absence of any system of social security, this can result in suffering for the whole family and the loss of the man's traditional bread-winning role. Even those with their own business experienced problems, as related by this shopkeeper:

Mm I'm a shopkeeper. Leishmaniasis since it damages your face, you will look ugly and you will have a bad looking face. When people come to my shop they just ask about my leishmaniasis and are not interested to buy anything. They say: "you look ugly". Leishmaniasis is from dirt. When